caCURE

A new caBIG® application for Collecting Patient Reported Health Data

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Agenda:

- The Health of Women Study
- Initial Launch
- The Data
- Findings from the Initial Launch
- Next Steps

The Health of Women Study (HOW)

- **Purpose:** Develop a new model research
 - First-ever, large online cohort study
 - Examine causes, treatment, prevention of breast cancer,
 - Identify predictors of survival and consequences of therapy
 - Designed to study up to one million women.

• Initial Launch:

- Directed to the current Love/Avon Army of Women
- ~30,000 women completed the first module to date

Collaborators:

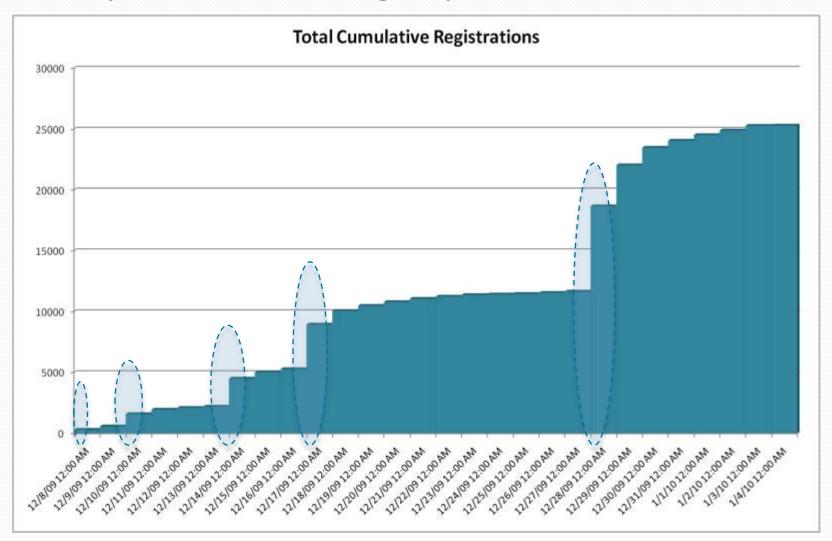
- The Dr. Susan Love Research Foundation,
- The Beckman Research Institute (COH),
- BIG Health Consortium[™]
- Tooling: caBIG® tools for secure online submission/handling of data

Module One Data: 175 questions arranged in 4 forms

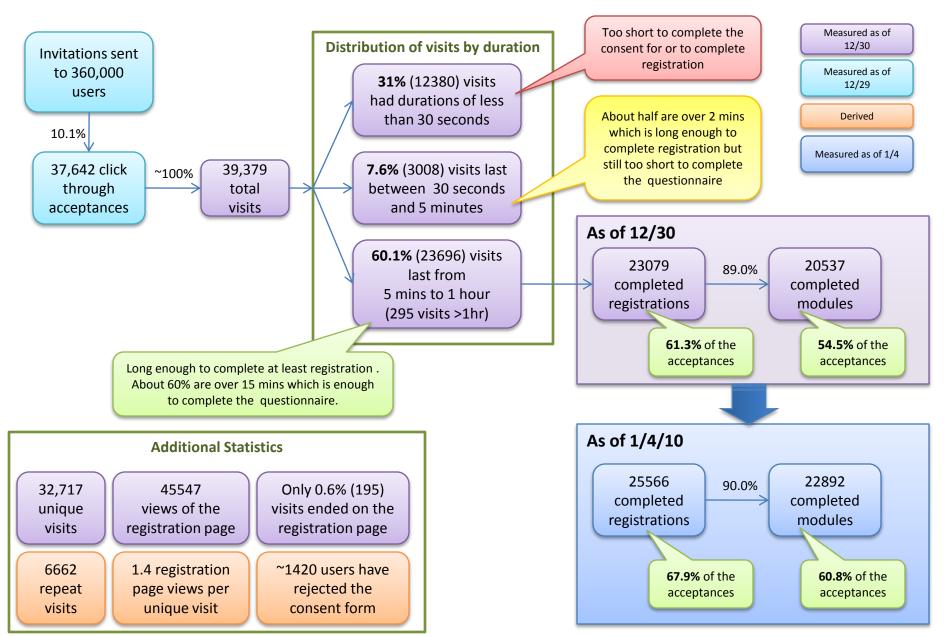
- **About Me:** gender, occupation, education, ethnicity
- My Reproductive Health: menstruation, birth control, fertility, pregnancy and nursing, menopause, hormonal therapies
- My Health As Of Today: general health and activity, height, weight, alcohol and tobacco usage, diet, sexual orientation and activity, health complaints, herbal remedies
- My Cancer: diagnoses and treatment

All data elements in the caDSR under caMATCH category

Participants invited in 5 groups



HOW study website flow analysis



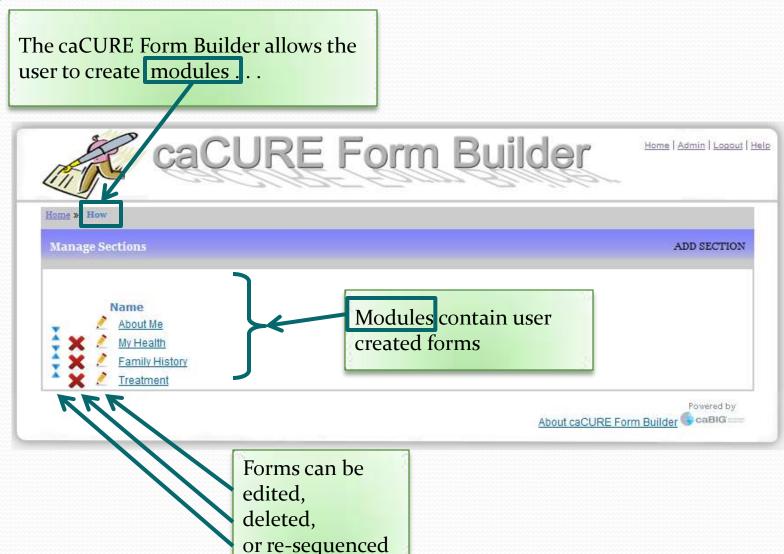
Findings from Phase One / Initial Launch

- We can predict required system capacity from well characterized arrival distributions
- The form technology needs complete overhaul to support release of new modules over time
- Data persistence must be revamped to allow for dynamic extensibility
- Data analytics needs to be reengineered to evolve with the forms and data

Phase 2 - caCURE

- Form Builder
 - Creates new modules, forms and questions
 - Uses Xforms for form representation
 - Supports edit, approve, pilot, publish life cycle
- Form Runner
 - Integrates easily with popular open source CMS systems
 - Persists data as JSON or XML
- Data Analytics
 - Allows declarative presentation semantics
 - Provides graphical analysis of selected data

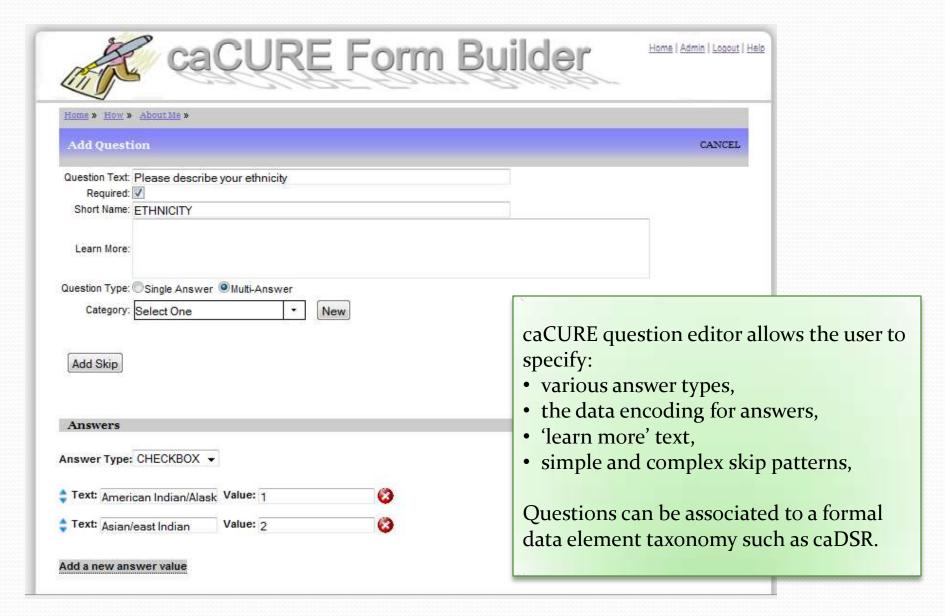
caCURE Form Builder: Creating modules and forms



The Forms contain Questions

caCU	RE Form Builder Home Admin Loquet He
Home » How » About Me About Me	ADD CONTENT ADD QUESTION ADD TABLE QUESTION IMPORT QUESTION
First Name	
💠 🗶 🔌 Middle Initial	caCURE Forms such as this 'About Me' form, contain the questions. This one will collect contact information.
💠 🗶 🤌 Last Name	
▲ 🗶 🚵 Zip	
	About caCURE Form Builder CaBIG

caCURE's Question Editor



Forms are published as XForms



When a caCURE form is published, it can be imbedded and styled as needed to be consistent with the rest of the sponsoring website.